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FMUP FACULDADE DE MEDICINA UNIVERSIDADE DO PORTO

Communicating food procedures to caregivers of patients with dysphagia in inpatient care

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Dissertação submetida para obtenção do grau de Mestre em Comunicação Clínica
Faculdade de Medicina da Universidade do Porto

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setembro 2018

Agradecimentos

À Professora Doutora Irene Carvalho, pela orientação e todo o apoio prestado durante o processo de realização do projeto, bem como pela motivação nos momentos de maior dificuldade.

À Professora Doutora Maria Assunção Matos, por ter aceitado participar nesta investigação, e por me mostrar sempre que eu não sou um "calimero"!

Às Unidades de Cuidados Continuados Integrados de Figueira, Paços de Ferreira e Ordem da Trindade, bem como Hospital Militar das Forças Armadas – Polo Porto, por me terem recebido de "braços abertos" e com entusiasmo perante o estudo que lhes foi apresentado.

Às equipas multidisciplinares, doentes e familiares presentes nos internamentos e que colaboraram neste estudo. Sem vocês, este estudo não seria possível! Um grande Obrigada!

Aos elementos da secretaria da FMUP, principalmente à "nossa" Sara e à Aida pela ajuda imprescindível que me deram nesta recta final!

A todos os meus colegas do Mestrado, por termos mostrado que a união efetivamente faz a força.

Às minhas amigas do coração: Ana, Alexandra, Juliana, Marisa, por me transmitirem força e bons momentos de conversa, quando parecia que o mundo ia acabar.

Ao José, pelo carinho, pela paciência e pela força em toda esta caminhada.

Aos meus cães: Dogui, por ter encarnado na perfeição o papel do "irmão" que eu nunca tive, e ao Ringo por transformar os meus dias cheios de energia e ser o meu companheiro na elaboração desta tese.

E porque os últimos são os primeiros, agradeço e dedico esta tese aos meus PAIS, os amores da minha vida, que fizeram de mim a pessoa que sou hoje. Tenho muito orgulho em vocês!

Sísifo

Recomeça…
Se puderes,
Sem angústia e sem pressa.
E os passos que deres,
Nesse caminho duro
Do futuro,
Dá-os em liberdade.
Enquanto não alcances
Não descanses.
De nenhum fruto queiras só metade.

E, nunca saciado,
Vai colhendo
Ilusões sucessivas no pomar
E vendo
Acordado,
O logro da aventura.
És homem, não te esqueças!
Só é tua a loucura
Onde, com lucidez, te reconheças.

Miguel Torga

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Caregivers' and health professionals' perceptions about food procedures in dysphagia: How do they communicate?

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Abstract

Dysphagia is a swallowing disorder that occurs following mechanical, neurological or prebisphagia disturbances, with negative consequences for patients functioning and quality of life. The food is an extremely social activitie that become compromised, affecting the interaction with others. The intervention in dysphagia presents a great failure of communication of the professionals to the patients and their caregivers on the necessity of the change. The aim of this study is to identify the experience of health professionals and of caregivers about the communication that exists between them about dysphagia.

We used the qualitative method, with the application of semi-structured interviews. Thematic analysis was used, and representative themes were chosen. We interviewed 13 nurses, 3 speech and language pathologists, 8 clinical assistants and 10 caregivers working in six inpatient unit care, in Portugal. Three subjects were identified in the interviews of caregivers and multidisciplinar team: 1. Knowledge about food procedures in dysphagia, 2. Conflicts with the multidisciplinary team of professionals/caregivers, and 3. Application of knowledge to/into practice.

Our Results show areas in which communication about dietary procedures between caregivers and health professionals can improve. They underscore the importance of professionals having more knowledge about dysphagia, communicating about risks, using basic language and implementing two-way conversation with caregivers to address

procedures. These concerns may promote greater awareness of dysphagia, which may lead to the promotion of patient health safety and reduced conflict with the team.

Keywords: Caregivers; Communication; Deglutition; Deglutition disorders; Dysphagia; Food procedures; Multidisciplinary Team

Introduction

Dysphagia is a swallowing disorder that occurs following mechanical, neurological or prebisphagia disturbances [1,3-7], with negative consequences for patients' functioning and quality of life. Patients with dysphagia often show complications that include malnutrition, dehydration, weight loss, pulmonary complications, pneumonia and, in the most severe cases, death [1-7].

To prevent these complications, careful eating procedures and food modifications are necessary as part of the treatment of patients with dysphagia. [2-5]. However, these feeding regimens often affect patients' psychosocial functioning. Loss of pleasure associated with food and eating might result from patients' inability to eat regular food or to eat it in regular ways. Food and eating are extremely social activities that become compromised, also affecting the interaction with others.

Negative effects on family dynamics occur, for example, when, at home, family members choose to eat without the presence of the patient when they are not eating the same food as the patient. Eating in public places such as parties and restaurants is also complicated. Food adaptation and its associated social aspects can also have an emotional impact, possibly generating feelings of anxiety, frustration, anger and fear, as well as uncertainty and insecurity related to dealing with dysphagia. In turn, dysphagia generally represents a heavy daily burden for caregivers in terms of preparing and delivering adequate meals, such as adapting the indicated food consistencies and observing contraindicated foods [6,7,8]. While these food-related procedures are crucial for patients' health and safety, caregivers (and patients) might find it difficult to observe them, especially if their understanding of the necessity for such procedures is limited.

Patients' family members or caregivers can play an important role in situations of dysphagia. Yet, they are frequently poorly supported by health care teams [7]. Caregivers can provide valuable practical and emotional support to patients with dysphagia. However, studies report a lack of professionals' communication with both patients and

their families in cases of dysphagia, as well as lack of awareness on the latter's part on the need to change diets. Patients and their family members perceive this process of diet changing as abrupt [7, 8]. Yet, direct verbal communication about all dysphagia procedures is rare, and is often omitted from family members. Health professionals also use technical language as part of their communication [5-7], but clear communication among patients, families and health teams might be essential in feeding decisions [8]. Communication gaps might prevent caregivers from realizing their potential as supporters of the patients and of the patients' needs. For example, if the need for diet changes is poorly understood, caregivers might provide inadequate food and risk the patient's health and safety.

In the literature on health care, communication failures among health professionals are the main cause of errors and adverse events in clinical care [9].

Communication failures between professionals and caregivers might likewise lead to errors, with consequences for the patient's well-being. For example, one study showed that lack of shared understanding of treatment risks and benefits, as well as of how treatment options fit within the patient's values and life circumstances, was associated with less adherence to treatment plans in cancer [12].

Communication is an important aspect of patient and caregiver satisfaction and complaints [8,9]. Communication allows access to individual preferences, needs and values when centered on the caregiver and on the patient [13]. Through such a communication framework, professsionals can not only understand caregivers' needs and values but also address their behaviors and attitudes within that context, namely regarding feeding procedures. In this model, professionals and caregivers present their own perspectives and articulate their needs and values. This ongoing sharing of useful information, in turn, helps to promote commitment to treatment plans [14].

Methods

This qualitative study was conducted in six inpatient care units in Porto, Portugal. The study received ethical approval by the National Commission for Data Protection and from the Ethics Committee of the Northern Health Regional Administration (ARSN), which is the government organization that oversees all inpatient care units in the North of the country. Participants were invited for the investigation receiving written and verbal information about the study. Those who agreed to participate signed an informed consent. Participation was voluntary, and a code was assigned to each case to ensure anonymity.

Sample

The sample includes 34 participants who agreed to take part in the study. They were 10 caregivers of patients with dysphagia receiving treatment in each of the six inpatient care units and 24 professionals who directly cared for the patients. Caregivers were eligible for the study if they were 18 years of age or older and had relatives in inpatient care for dysphagia. The professionals who were directly involved in the care of these patients were 13 nurses, three speech and language pathologists and eight clinical assistants.

The 10 caregivers were nine women and one man (*median* age = 55.5 years old, ranging from 45 to 70). They were patients' daughters (*n* = 7), niece (*n* = 1), father (*n* = 1), and mother (*n* = 1). Their education levels were the 4th (*n* = 1), 6th (*n* =1), 9th (*n* = 1), 12th (*n* = 3) grades and college degrees (*n* = 4).

The 13 nurses were 12 women and one man (*median* age = 29 years old, ranging from 22 to 43). They had received training on dysphagia as part of their degree. All three speech and language pathologists were women (*median* age = 32 years old, ranging from 23 to 46), and all had received postgraduate education on dysphagia. The eight clinical assistants were seven women and one man (*median* age = 35 years old, ranging from 19 to 52). Their education levels were the 9th grade (*n* = 2) and the 12th grade (*n* = 6). Three clinical assistants reported having received training in dysphagia, whereas five reported not having training in dysphagia.

Instruments

To elicit participants' perspectives in their own words, we used semi-structured interviews. The semi-structured interview allows flexibility and adaptation of the questions according to the flow of the "conversation" and according to the interviewee, without limiting the responses [11].

Our interview consisted of open-ended questions about participants' perceptions regarding food procedures in dysphagia and about caregiver-professional communication on this subject. The interview began with a general question that introduced the topic for further probing: "Tell me about your experience of being here in the hospital with [the patient/and the caregiver] in these cases of difficulties with eating". The following questions were, "Which procedures are necessary with the patient, regarding food and eating/drinking?" and "What kinds of information were given [to you/and by you] about

this process? Tell me how it goes since the beginning". Probing followed for such aspects as "dos" and "don'ts" of food procedures, greater and lesser difficulties associated with this food-related treatment, who prepares the food, who feeds the patient, with what, as well as examples of specific situations. Caregivers were further asked about what kinds of information/help they would like to receive from professionals, if any.

Socio-demographic information was also obtained from the participants, including specific training that professionals received on dysphagia.

Procedures

This study consisted of applying semi-structured interviews to caregivers of patients with dysphagia and to the multidisciplinary team of professionals who were caring for these patients in the six different inpatient care units. A professional inside each health care unit was responsible for signaling the patients with dysphagia who received visits from caregivers, and for approaching the respective multidisciplinary teams and the caregivers about participation in the study. The semi-structured interviews took place in a private setting of the respective health care unit, and were individual, face-to-face interviews conducted in an informal and conversational tone. All interviews were audiotaped with participants' consent. To ensure data quality, participants were informed that the researchers were external to the inpatient care units and that the study had no implications for their individual status or treatment in this or in other institutions. In addition, focus was placed on the establishment of a rapport with each participant.

Analysis

All the audiotaped interviews were transcribed verbatim. A thematic analysis was then applied to the data in the software NVivo 12. A thematic analysis is a procedure for identifiying, analyzing, organizing, describing, and reporting themes found in the interviews [10]. The goal is to produce a rich and detailed, yet complex account of data. according to the principles of the qualitative method [10].

Following the procedures of thematic analysis, the process began with (re)reading all interviews for familiarization with the data, followed by generation of initial codes, search for themes, review of themes, and theme definition and naming [10]. One researcher coded all interviews and the other coded 10 interviews independently. Minor disagreements were observed between the two, which were reconciled through consensus.

Results

The themes emerging from the qualitative analysis of the interviews with the patients' caregivers are presented first, followed by the themes emerging from the interviews with the multidisciplinary team of professionals. Then, the themes from these two groups of participants are integrated and compared. Participants are identified in the text by professional category/status and identification number: C – Caregivers; N – Nurses; SLP – Speech and Language Pathologists; and CA – Clinical Assistants.

Caregivers' experiences about food procedures in dysphagia and communication with professionals in inpatient care

Three themes emerged from the interviews with the caregivers: 1. *Knowledge about food procedures in dysphagia,* 2. *Conflicts with the multidisciplinary team of professionals,* and 3. *Application of knowledge to practice*.

1. *Knowledge about food procedures in dysphagia*

Caregivers revealed relying on two types of sources of knowledge about food procedures in dysphagia: 1.1. *Knowledge transmitted by the team of professionals* and 1.2. *Informal knowledge*. Two additional subthemes emerged under the first subtheme: 1.1.1. *Limited knowledge and post-fact knowledge transmitted by the team,* and 1.1.2. *Reasons for the limited knowledge transmitted*. All these subthemes are presented below.

1.1. *Knowledge transmitted by the team of professionals*

In the interviews, all caregivers considered that professionals gave them information about some aspect of dysphagia. This information included the difficulty in swallowing and some risks that this situation can generate. As part of the information received from professionals, all relatives also mentioned the need to adapt the food and/or use the thickener in liquids due to the patient's swallowing difficulties:

> The speech therapist had a meeting with me and explained the difficulty that [the patient] had in swallowing the food and the risks that it could cause. ... I remember that she spoke about the risk of choking, food moving into the airways which could lead to a state of coma, almost, let's say. This was conveyed to me. She also spoke about the type of food and the consistency of the liquids with the thickener. (C27)

Some caregivers referred that they were taught to prepare the thickener: "I feel capable of preparing the food with the thickener ... Right at the beginning, the nurses explained

the quantity of thickener that I should use. They've already [explained] twice or three times" (C28). Several additionally revealed that professionals asked them not to bring food from outside the facility because of its consistency requiring adjustment with the thickener or other modifications: "The SLP recommended that, at this stage, I should not bring anything, so I am respecting that ... I've already brought the thickener, and my mother drank her tea at the caffé ... but she was very upset." (C31).

1.1.1. *Limited knowledge and post-fact knowledge transmitted by the team*

The knowledge that caregivers received from the team of professionals was, however, incomplete. Several caregivers reported that they had not received information about the type of diet and food consistencies to be given to the patient, or the reasons for this diet and for food or liquid modifications, as well as about how to prepare the thickener: "[The nurse] said to me, 'You have the powder and water by the bedside, you can prepare it',... and I said, 'But I don't know the quantities, they didn't explain.' And then, they would prepare it ... They never told me the kind of quantity of thickener to put in the liquids" (C29). In addition, some caregivers reported that they were uninformed about the risks associated with eating in dysphagia:

> The nurse warned me to not give normal water, it had to be with the thickener, ... and they provided the can. So there was this approach that I unfortunately already knew, ... but there was no more information about it ... Despite nobody telling us, I know that if [the patient] drank a glass of water, he'd choke … The water could go into the lungs … I know this, unfortunately, because of what happened in the past [with a different family member] (C25).

At times, the risks and procedures associated with dysphagia (for example, a modified diet, or the patient's position when eating) were only addressed after the fact, that is, after observation of caregivers engaging in some inappropriate behavior that might risk the patient's condition: "A person here, I don't know if she was a nurse or a clinical assistant, told me that my sister brought things that weren't appropriate for my father, and they called [my sister's] attention." (C25).

1.1.2. *Reasons for the limited knowledge transmitted*

In caregivers' perspectives, professionals provide limited information about the patients based on three assumptions. First, the presumption that caregivers already possess the knowledge on dysphagia: "I've never talked to anyone in the team about this

[food procedures and risks], like they did with my sister, because maybe I understand it better" (C25). This assumption justifies the fact that the information is given to caregivers only after the fact, that is, when caregivers' misinformed behaviors violate such presumption (as illustrated by this same caregiver in the theme above). Second, the notion that, in inpatient care, professionals are present to take care of the patient, thus reducing the need for informing caregivers:

> When my father is thirsty, I call the nurse and he puts the powder in the water. I'm afraid that I'll do it wrong. They never told me how to do it, but I also think that it's best that they do it. That way I'm sure that it'll be well done. (C34)

Third, the idea that professionals themselves have limited knowledge about the patient:"We always have the tendency to ask nurses what happened, if it's going well or not, and they have answered within their limits. I know that there are secrets, doctors don't tell nurses everything about my son. I think. [But] everybody in the team has informed us within the capacities that they have" (C26)

Professionals' unavailability to communicate with the families also limits the information received:

> Beacuse I'm a health professional. I'd like that the doctors were more transparent with me. How shall I say? It has to be me who has the initiative to ask about aspects like medication changes, for example. (C31)

Finally, knowledge transmitted by the team was limited also due to the use of technical language and provision of information with a "negative attitude":

> The doctor came to me and said that, at the time of discharge, my father should take X medication and X food supplements. And I stared at her and said, "Excuse me?! I don't know what that is!" And the doctor said, "How don't you know?!" And I just told her, "Maybe because I don't have training in this area!!" Look, with such arrogance, all that technical language. The only reason I didn't reply was because I knew that my father might have to come here again. (C29)

1.2. *Informal knowledge*

In addition to the information received from the team of professionals, caregivers rely on informal sources of knowledge to learn about dysphagia. In this sample, such sources of knowledge included previous experiences with this or other patients ("I already knew about this, the thickener, because my husband's mother had a stroke and had used it before" (C25)), as well as observation of what happens and does not happen in the context of inpatient care: "My aunt eats pureed food and drinks with a powder. I only

know this because I was here one weekend and I saw" (C33), or "I don't see any alteration in the food [he eats here]" (C25). However, learning informally does not ensure that caregivers understand the reasons behind a particular procedure if these are not explicitly explained. For example, a caregiver attributed the need for modified food to her father's lack of dental plaque:

> Food must be all pureed, mash-based, or very well grounded. And that's what he has been complying with! My father used to have dental plaque but now he doesn't adapt to it. So it has to be this way. (C29)

Caregivers fill in the gaps in knowledge with their own explanations. In this process, they might sense that they possess a very good understanding of dysphagia and of related feeding procedures, without the need for further information:

> Deep down, we get it. When there was the team meeting, they told us that they were available to address any doubts that we had about anything. But truth is, time passes and we already don't have any doubts. My father's age turns out to be everything! (C28)

2. *Conflicts with the multidisciplinary team*

Caregivers appreciate that professionals are willing to respond to their questions and that channels of communication are open in both (caregiver-professional) directions:

> Here [professionals] put people very much at ease … Yesterday I had the meeting with the team [of professionals], and it was very helpful. Whatever we need, we can go there … It's a little bit both ways. When it was those things that my mother used to do for them to evaluate her head, they'd call me and tell me. And there have been things that I ask the nurse about. We speak, from both parts. (C30)

Communication in both directions is important for caregivers, and professionals' availability to answer questions, alone, is insufficient. Even if admitting that professionals respond to their needs and questions when approached, some caregivers would prefer that professionals would show more initiative in communicating with them. Without this initiative, the burden of starting the interaction falls on caregivers, which generates negative feelings, such as the fear of being inconvenient:

> The information that I obtained from the professionals here, it was more I who looked for them … I think that they [professionals] should approach families more … There's a lack of initiative on the part of professionals. But I think that they've done a good work, overall. But I think that it shouldn't start from us. How shall I

> say? The family might feel, how shall I say?, that they perceive us as annoying. I think that there could be more feedback, a meeting asking the family if there's doubts, for example. (C27)

Caregivers additionally resent the "negative attitudes" that they perceive in professionals' communication with them. These attitudes included the use of technical language and arrogance illustrated earlier, as well as professionals' apparent unwillingness to communicate, which leave caregivers feeling ignored and little at ease about how to proceed:

> It's me who has to ask things to nurses, why don't they speak? They even pretend that they don't see me, I don't know. And then they complain that things [that I bring] are wrong ... I had to ask what it was for, because they didn't even explain. But they explained against their will. What do I know about what my aunt has?! … I can't guess! (C33)

Caregivers further resent that information is transmitted to them only at the moment of the patient's discharge from the hospital, and advocate earlier and more frequent interactions with the team of professionals, in line with the importance that they place on maintaining the communication channels open in both directions.

> I think that this dialogue between doctor and family should be closer, not from time to time. It always has to start from our own initiative. [My father] has been here once already, and when it's time for his discharge, then, they're in a hurry [to talk to us]! (C29)

In their views, more inter-professional communication would also contribute to a more effective flow of information exchange, particularly regarding the patient's health status:

> I want to know if my father is better or not, the clinical assistant won't know, that's normal, nurses say that it has to be the doctor in charge, and before I find the doctor? It's very complicated … If only the doctor can talk about the situation, at least she could leave something written … Ok, I understand that these are inpatient care norms. They should place themselves on the side of the family … Regarding communication, there should be that interaction between doctor, the rest of the team and the family. (C29)

Professionals' lack of initiative to provide (more frequent) information (before the moment of patient discharge), as well as the negative attitudes uncovered under Conflicts with the multidisciplinary team, are also part of the Reasons for the limited knowledge transmitted to caregivers, presented above. This indicates that several reasons for the

limited information transmitted to caregivers are associated with conflict, or antagonism with the multidisciplinary team of professionals.

3. *Application of knowledge into practice*

Caregivers in inpatient care participate in the activities of feeding their hospitalized patients: “The only participation we have [with the patient] is during meal times, lunch or mid-afternoon snack” (C29). Caregivers base feeding procedures on the knowledge acquired through the sources of information presented earlier: 1.1. Knowledge transmitted by professionals and 1.2. Informal knowledge.

Regarding 1.1. Knowledge transmitted by professionals, caregivers in this sample revealed that they comply with the recommendations and information that the professionals communicated about food procedures, even when these go against the patient’s desires:

> For him, it’s an agony. He becomes very aggressive because he wants to eat normally. Before, I used to bring food, he’d ask me. But the speech therapist and the nurses talked with me. The therapist explained that the food might pass into his lungs and he might run the risk of having pneumonia. But she allowed me to bring food all the same. Now I bring what we agreed upon, it’s more pureed food … all mashed. (C32)

However, the information that professionals convey to caregivers is limited, as described earlier, and, in the absence of this formal knowledge, caregivers rely on 1.2. Informal knowledge as a guide for their courses of action. This represents relying on informal knowledge’s subthemes as well, that is, on caregivers’ past experiences with patients and on what caregivers observe being done (and not done) in the institution, as well as on providing personal explanations to fill in the gaps in knowledge and, at times, sensing that no further information on feeding procedures is needed.

As part of this informal knowledge, caregivers additionally proceed according to what they (and the patient) value, and according to their own assessment of the patient. For example, caregivers enjoy bringing “treats” for the patients in the form of food and drinks: "I’ve already asked … They say it’s best that we don’t bring [food from home]. But, you know, a little treat, for her to feel like, but they don’t advise that all that much! They say that it’s advisable to avoid that people eat those things, that it’s safer to eat what’s here"(C28). Caregivers assess the consequences of their actions by monitoring the patient’s symptoms or condition and by attributing a degree of severity to such symptoms:

"Once in a while we bring a little cake, but it's rare. We've never asked anyone [about the food we bring] because he chokes only with water. He can eat the rest "(C34). Caregivers presume that professionals' silence constitutes proof that their ideas and actions are correct. Otherwise, professionals would inform them of the contrary: "They've never made any observations about the treats we bring … In principle, if they haven't made any observations it's because the food is adequate to the diet that my father is doing"(C25)

The choice between proceeding according to what caregivers (and the patients) value and what professionals recommend may be difficult. When professional-caregiver communication is insufficient, professionals' recommendations may be completely disregarded for lack of information, especially if communication is insufficient because of reasons that raise professional-caregiver conflict, identified earlier (e.g., leaving caregivers feeling ignored or mistreated). In these cases, even if caregivers comply with professionals' recommendations while in the hospital, they might intend to proceed otherwise once the patient is out of the hospital:

> To be honest, I'm a little tired. I just want to take my aunt away from this place. I feel that she's tired of being here. I think that they bicker for just anything … if we bring food, it had to be other food … I'm really anxious to take her out of here. Then, we'll do it our way and no one has anything to do with it. (C33)

When information is limited and common understanding is lacking, patients' symptoms might be apparent for caregivers to monitor, but might be attributed a low degree of severity that legitimizes caregivers' values and intentions:

> I brought [some cakes] because she's tired of mashed food. It was a pleasure for me to see how happy she was. The nurses said that I couldn't, because she'd choke. Anyway, just because she choked one time or another, does she have to eat such a strict diet? I find it an exaggeration … Now I give her more yogurts and such. ... But I still find it an exaggeration. I already don't even bring anything, to not get into trouble. Like I say, when she goes home it'll be different. (C33)

Professionals' experiences about food procedures in dysphagia and communication with caregivers in inpatient care

In parallel with the themes uncovered in caregivers' interviews, the themes emerging from professionals' interviews were 1. *Knowledge about dysphagia and food-related procedures,* 2. *Conflicts with caregivers*, and 3. *Application of knowledge into*

practice: Conflict management.

1. Knowledge about dysphagia and food-related procedures

1.1. *Formal knowledge and informal functioning*

Professionals' knowledge about dysphagia was acquired through formal training, especially in the cases of nurses and of speech and language pathologists. Clinical assistants deal with dysphagia in daily practice, although some also reported having received training in this area. According to professionals, dysphagia assessment is formally the responsibility of the speech and language pathologist: "It is entirely my responsibility to evaluate swallowing, whenever a new patient comes in." (SLP24). However, speech therapists spend considerably fewer hours in inpatient care than other professionals do, and patients with dysphagia are often signaled by clinical assistants instead. Clinical assistants are present at the time of the meals, feeding the patients and recognize dysphagia through the patient's signs while eating: "(...) if the patient cough or choke" (CA, 15). In addition, nurses consult discharge notes from patients' previous hospitalizations, as a way of assessing the presence of dysphagia: "(...) if you have described in the discharge note where the patient comes from, we assume that he has dysphagia and we take care of him." (N, 3). If such information is lacking, assessment is conducted through trial-and-error, based on patient presentation: "Usually, it's through trial-and-error. We typically start with a soft diet, we see the patients who do not have teeth, or whether they have speech difficulties... and then we progress" (N, 5).

1.2. *Limits of formal knowledge and intra-team communication*

Participants acknowledged that different professional categories possess different levels of knowledge on dysphagia. Some professionals considered that a good understanding about dysphagia exists within the team, without the need for further training: "To retract we could have training of dysphagia ... But I think there are no difficulties, because we understand things ..." (N, 7). However, others called attention to different levels of awareness about dysphagia existing within the team, and most professionals called for the need of training in dysphagia for the entire team: "Training in dysphagia is a fundamental point for the whole team! Obviously at different levels. Doctors and nurses on the same level, and clinical assistants on another, but we urgently need"(N, 11). The knowledge that team members possess has implications for communication with caregivers and patients, namely regarding the quality of the

information conveyed (or not conveyed). Depending on their knowledge, professionals may feel more or less at ease communicating some information, and might prefer to refer caregivers or patients to team members from a different professional background: "I don't think it's information that is up to me to give ... I can give wrong, or not totally correct information, so I prefer to report to the nursing staff. (CA, 18)".

Regarding feeding procedures, professionals revealed the need to be constantly adapting food for the patients. Because of possible lack of awareness within the team, food preparation requires special attention. Both nurses and clinical assistants are in charge of this task, but nurses supervise the process to ensure that food is adequately adapted: "It's our responsibility to have the correct preparation, since there are assistants who are aware of this type of risks, but others who are not... That's why nurses always have to supervise this kind of thing." (N, 3). These professionals also mentioned difficulties in contraindicated foods and in diet preparion occurring in the unit's kitchen: "The food is not always well prepared, but the soups ... must always be prepared to be? thicker." (N, 11). To compensate for eventual food misadaptation, professionals carefully monitor the patients when they are eating: "The preparation of the consistencies, it depends... Sometimes it works better, sometimes worse. We have to pay attention to the patient and see how he swallows... if we cannot, we have to take a little more time to eat with him." (N, 2).

Communication among team members is considered a fundamental part of caring for the patient with dysphagia. Due to the strict measures associated with eating, these patients require the alignement of the correct procedures among all involved parts: "The patient with dysphagia requires double the amount of attention [of any other patient], and we have to make sure that everyone complies with the type of consistency that they should use." (N, 4). To accomplish this goal and minimize mistakes, some teams use information with individualized diets for each patient, laid out by the speech therapist for all team members:

> But we also have a sheet in the room made by SLP that guides us a lot... If we have any questions we go there and consult it. For example, there are cases that the patients only have dysphagia for liquids, and their food is normal ... we have to pay attention! (CA,15)

Professionals value the daily presence of speech and language pathologists and the knowledge that they convey to the team: "The fact that the patients are evaluated by the speech and language pathologist, who is there daily and communicates the procedures to

the team, is very valuable..." (N, 10). However, although recognizing that speech and language pathologists should be in the inpatient care unit more frequently, the remaining team members need to adapt to working without the constant presence of this professional. In the absence of the speech therapist, nurses assume the role of coordinating the team. Since there are always nurses in the inpatient care units, they are responsible for the procedures delivered to the patients and pass the speech and language pathologist's information along to the clinical assistants and to the kitchen staff: "There's a plan drawn up by the speech and language pathologist (...) for each patient with dysphagia, which is transmitted to us and to the family... and then we go back to recapitulate to the family." (N, 2), and "We have to make sure that everyone complies with the kind of consistency he (the patient) should use." (N, 3). Nevertheless, they consider the presence of speech and language pathologists as crucial when more complicated cases appear:

> The SLP is only required in more specific cases, the more complicated cases ... for example, there was a patient who had a permament cough. The SLP recommended the use of an SNG. Despite this and not being there 24 hours a day, we managed to control the situation and began to administer oral. But it is always evaluated taking into account the history of the patient, the clinical process, and which state presents to be when they come to our unit. (N, 10).

1.3. *Knowledge transmitted to caregivers*

The information conveyed to caregivers and patients varies according to the professional category of the team member. Nurses referred that they typically approach dysphagia and food procedures with caregivers and patients according to the patient's state of consciousness, and in simple terms, linking patients' symptoms with the need for diet changes: "Then we transmit to the patient that we notice that he chokes, that he cannot chew, and that is why it has to be pureed food... we try to explain everything according to the [patient's] state of consciousness." (N, 5). In general, professionals said that they offer instructions about contraindicated food and explain the necessary type of food preparation. They associate this information with patient's risk of choking, and with the need for the patient to eat food with a different consistency using plain language:

> The family advises not to provide water or any liquid food, which now has to be used with thickener and explain what the goal is. I explain that it is a powder, which dilutes, and increases consistency and the purpose is to prevent the patient from choking. Normally we use another kind of language...I don't think it's

dysphagia, but rather the patient can choke (CA, 21).

In turn, speech and language pathologists explain dysphagia and food procedures in more detail, also using plain language and visual aids:

> Both the patient and the family started by gathering and it was explained what dysphagia is, its consequences and the type of diet the patient has to do. Of course, it is important to keep in mind the terminology that is used... I usually use simple drawings and videos, which usually have a good adherence to the level of understanding. (SLP, 23).

Speech and language pathologists additionally discsuss possible risks. They revealed that they initially address the importance of following instructions, and then explain that non-compliance could lead to pneumonia and death.

1.3.1. *Limited and post-fact knowledge transmitted by the team*

Choking is a visible symptom that the patient might present, and constitutes the risk that professionals tend to mention to caregivers. Team members other than speech and language pathologists occasionally also explain other, more serious, risks involved in dysphagia, but they tend to do so after the fact, that is, after caregivers bring food from the outside or put the patient's health at risk, for example, as a last resort when everything else has failed: "The whole team has already leaned against the wall, and has already said that it is harmful to the mother, which does not do him good, and it was spoken on the possibility of death." (N, 6).

1.3.2. *Reasons for the limited knowledge transmitted*

Professionals other than speech and language pathologists only occasionally address risks associated with non-compliance with food procedures under the premise that instructions and associating type of diet with patient symptoms (e.g., choking), in plain language, will be sufficient to ensure caregivers' understanding and compliance. Thus, (other) risks are mentioned only after the fact, when caregivers show resistance or do not seem to understand the information transmitted (wgucg is detected, for example, through observation of patient-caregiver interactions):

> Initially I do not address the issue of risks ... I start with the informational part, the type of diet and consistency, if you do not understand, I'll take the risks to alert you! (...) I think that there is no need, or we do not take into account the importance of the risks at first ... We evaluate the care that people have with the patient, and

then we speak or not according to the needs. (N, 7).

In these professionals' views, risks are alarming for caregivers. They are thus presented on a needs-based plan with the purpose of alerting and attempting to persuade caregivers and patients who are observed having difficulties with understanding or compliance,

Professionals also presume that caregivers will ask the team about food procedures before feeding the patient, although they recognized that only a few caregivers do ask: "There is a caregiver or other who is careful to ask, 'can I bring this, can I bring that, can I eat this'..." (N, 1), Behind this assumption is the idea that, in inpatient care, professionals take care of the patients, and caregivers assume an ancillary role, acting only after obtaining information from professionals and according to it.

2. *Conflicts with caregivers*

Caregivers failing to ask professionals about food procedures before feeding the patients, or opposing resistance to professionals' instructions, is motive for surprise: "(...) give food on the sly and we give it to them. We can even say that they cannot give, however when we enter the room we get surprised that they are already giving." (CA, 14). From professionals' points of view, these and other attitudes, such as bringing food from outside the facility and risking the patient's life, show ignorance about dysphagia on the part of caregivers, or lack of understanding about the information that professionals conveyed, even when caregivers, themselves, asked for that information:

> I am reminded of a case that we had here that a patient's daughter asked if she could give water to the mother to help, and the assistant said yes, but that she had to add the thickener. After some time she came to say that the mixture was not made, she was mixing the water with moisturizing cream. (N, 13)

Additionally, some caregivers effectively undervalue dysphagia, in professionals' views: "(...) families identify that we are exaggerating and that it will not be like this ... they want to give that little treat to the family member and give hidden ones many times." (N, 1).

3. *Application of knowledge into practice: conflict management*

To manage these situations, professionals might add information on the risks of non-compliance with food procedures to previous information already given, to raise caregivers' state of alert, as mentioned above. They might also repeat the explanation given before, under the premise that caregivers did not understand it (or forgot it):

> There are caregivers who don't understand, they bring food from the outside, don't

> ask us if they can give it [to the patient], we must always follow them ... we know them ... they bring cakes and because they are hard they think that the patient can eat and we must repeat the explanations continually. (N, 3).

In addition, some professionals emphasized the importance of actively listening to the patient and family members to understand the other side:

> The important thing is to create alliance, negotiate... Listen to the other, and then give the explanation. There may be valid reasons for the patient or family not wanting to follow that diet... What I have learned is that we have to be available to listen and accept, even though it is often not what we wanted to hear "and" I remember being told "The truth is that behind every patient, there is a life story... and the patient has the freedom to choose what he wants for him!" (SLP, 22)

As part of understanding the other side, professionals might allow some flexibility and exceptions, showing human sensitivity: "Sometimes exceptions are made in food, I won't lie, we don't change liquids, but a simple cake or so, we do... I will not say no..." (N, 5). These exceptions are more likely as professionals spend more time with the patient, creating empathy, and under the idea that these patients face a limited scenario ahead:

> It is a patient who ends up creating a connection, I do not know if it is beneficial or not, but also has no future prospects for life. No doubt our human part says that although there are things described in the literature saying they are like this, in practical life they are not. (N, 4)

These professionals are sensitive to the changes in life involved in dysphagia and to the initial resistances to changing diets that they observe in a large part of caregivers and patients:

> The most difficult part is to manage the patient with conscious and oriented dysphagia who thinks, "Before, I ate chicken and rice, and now I'm eating some popes?" ... to see their impaired state is not easy. And in addition, they have to share a table in the coffee shop and they want to eat the same diet that any other patient is eating. This period of acceptance is very difficult! Very, very difficult! They are very resistant. (N, 9).

By virtue of the time that patients with dysphagia spend in inpatient care, they acquire a special status for professionals, despite the constant food preparation that they require and the greater supervision that they need, more than any other patients, at meal times (or because of these aspects). Professionals revealed that they establish a rapport with these patients while, at the same tine, recognizing the difficulties of dealing with their reactions

to diet changes: mood swings: "We have a different connection with this type of patients because they spend periods of months here. The reaction of the patient has been difficult, when he joined the general diet, he had no swallowing changes and now he is already eating pureed diet?" (N, 6).

Professionals explained that, as a rule, whenever a situation requires attention, it is brought to discussion among the multidisciplinary team members. Professionals consider that intra-team communication is effective and helps to resolve the situation: "Most of the time they [clinical assistants] are that warn us of food coming from outside the hospital because they go more to the guest rooms or even find hidden food. Often families ask for other foods to the helpers and they always report to us. We have good communication!" (N, 7). Decisions depend on the situation and on the team: "When there is hidden feeding, this information is transmitted to the multidisciplinary team. Afterwards it depends on the attitude of the multidisciplinary team." (CA, 15). However, professionals noted that an attitude of pacience, without giving up, helps to achieve professional-caregiver agreement: "The patient showed more resistance, it was necessary to insist, we had to be patient on our part, but it is going very well." (CA, 17).

Professionals highlight the frequent changes in these patients' health status: "Maybe increased secretions, noisy breathing, this happens. A few aspiration pneumonias, and some episodes of choking or vomiting." (N, 12).

Interconnection between caregivers opinions and multidisciplinary team

In the interviews conducted with caregivers and the multidisciplinary team, both admitted that it is not easy to feed a patient with dysphagia due to adaptations in the food: "The most difficult thing is to manage the patient with conscious and dysphagia that before he ate chicken and rice and now I'm eating pureed diet?... Seeing their impaired state ... is not easy. (N, 5)", and "Also the presentation is not very pleasant. I understand if it was me I was the same ... they always say "oh always this always this!" (C, 26).
Most of the multidisciplinary team referred to take initiative on information on dysphagia for caregivers. In turn, caregiver opinions were divided. Although some have said that they have to be questioning the professionals, others have stated that the team transmitted the information clearly.

Concerning the transmission of information, it has been verified that professionals transmit information about dysphagia, but rarely communicate the risks. On the other hand, it is verified that caregivers approached the knowledge of some procedures of

dysphagia: "I know that if he drank a glass of water it would be clogged ... it has to be thickened". (C, 25)

When asked about the food coming from outside the inpatient care, almost all caregivers reported bringing a "treat", but they said that it is appropriate for the patient and that they talk to the team. On the contrary, professionals said that most caregivers bring food without the team's consent, and even provide it in secret.

Discussion

The results showed that some health professionals present difficulties in the assessment of dysphagia, recognizing that the presence of a speech and language pathologist in the unit care would be important. Moreover, there are teams that already have a speech and language pathologist therapist to assess and intervene with dysphagia mentioning that it is very positive and important to transmit information. We could verify this in another research study where it is recognized that this professional is indicated to share strategies to other professionals [7].

The moment of communicating dysphagia to caregivers is usually the nurses responsibility and, sometimes, of speech and language pathologist. Most of the interviewed nurses said that they explained to caregivers about the specific diet change and adaptations to be made, but did not address the risks of dysphagia because they were afraid of raising concerns. They also said that risks are only addressed when there is an incident with the patient. Regarding the speech and language pathologists interviewed, all stated that they explain the procedures, as well as the risks.

Health professionals acknowledged that dysphagia training would be an asset to the entire team, which could contribute to improved clinical practice as well as communication of dysphagia procedures and risks to caregivers.

All members of the multidisciplinary team have admitted that they have seen caregivers bring food from outside the hospitals. Some foods were provided in the sack, while other caregivers are careful to question whether the food is indicated or not. This aspect may be related to the fact that the caregivers have effectively understood what dysphagia implies or, on the other hand, they devalue the situation raising the hypothesis of communication failure [7]. On the other hand, some caregivers reported that they take food from outside the hospital to give to the patient as a form of "treat" making associations to social and cultural values as justification for this attitude [6-8]. In addition, another hypothesis can be raised once if the food provided to the patients is

contraindicated and the relatives do not value the care to be taken in dysphagia, patient exacerbations may occur due to respiratory infections/aspiration pneumonia or even death.

In inpatient care, visiting caregivers of patients with dysphagia actively participate in their meals, feeding them, and they value the presence of a two-way communication with the multidisciplinary team of professionals in this context. Caregivers rely on such communication to learn about the patient's health status and about how to proceed in feeding activities. They form alliances with the professionals in providing care for the patients on the basis of this communication and exchange of information that includes the understanding of feeding procedures, reasons and associated benefits and risks, However, when communication fails and information is insufficient or provided in a disrespectful manner, from caregivers' point of view, they favor informal knowledge that they might have on dysphagia and aspects that are important to them, over professionals' recommendations, which might put the patient's health at risk.

Some of the caregivers reported that professionals lack initiative in communication, use technical language and do not communicate clearly the procedures [6-8]. In this sense, some of the dysphagia procedures incorrectly applied by caregivers may be related to communication failures transmitted by professionals, and there is a need for greater awareness of this issue.

We must acknowledge as a limitation in this study the fact that the interviews were not performed to the patients. Interviews were given only to caregivers and multidisciplinary team, as our aim was to understand the health professionals, since they can explain the procedures and risks of the dysphagia, communicating directly to the patients and caregivers. We believed it to be an interesting knowledge from this perspective.

Moreover, the results obtained in this study allowed knowing the perceptions of the multidisciplinary team and the caregivers about the existing communication on dysphagia in some care units of Portugal. This allowed to support the scarce international studies carried out in this subject and to raise new subjects, which can help and improve future practice inpatient care.

Conclusion

Results show areas in which communication about dietary procedures between caregivers and health professionals can improve. They underscore the importance of

professionals having more knowledge about dysphagia, communicating about the type of diet and its risks, using basic language and implementing two-way conversation with caregivers to address procedures. These concerns may promote greater awareness of dysphagia in family members, which may lead to the promotion of patient health safety and reduced conflict with the team.

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Using a visual poster communicating dysphagia-specific food procedures as a complementary means of information to caregivers in inpatient care: usability and impact

Article submitted to the journal "Dysphagia"

Title

Using a visual poster communicating dysphagia-specific food procedures as a complementary means of information to caregivers in inpatient care: usability and impact.

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Abstract

Dysphagia is a swallowing disorder that can be associated with clinically relevant complications, and caregivers can play a fundamental role in this process. However, studies show a lack of professional-caregiver communication in dysphagia, and caregivers' need for more information. Communicating dysphagia-specific food procedures through a visual poster might bridge professional-caregiver communication gaps, with consequences for the patient's health. The aim of this study is to evaluate the use of such a poster at two levels: utility from the point of view of the caregivers, and impact on patients' health. Forty-two patients with dysphagia were recruited from five inpatient care units in Portugal. They were randomly assigned to control and experimental groups. A poster with pictorial information about dysphagia-specific food procedures, designed for caregivers, was posted by the bed of patients in the experimental group. Patients' health status was assessed before and, again, one month after placement of the poster on four dysphagia-related aspects (respectively, with the GUSS, the FOIS, the OHAT, and the MNA). Caregivers of the patients in the experimental group evaluated the poster's utility through a questionnaire answered at the end of the study. About 81% of the caregivers reported that the poster added new information to their knowledge. The

poster had significantly positive effects on two of patients' assessed health aspects (risk of aspiration while swallowing and nutritional status). A poster with pictorial information is effective in increasing awareness about dysphagia-specific information among caregivers of patients followed in inpatient care, with benefits for the patients' health.
Keywords: Dysphagia; Communication signs; Deglutition; Deglutition disorders; Inpatient care; Caregivers; Health

Introduction

Dysphagia is a swallowing disorder associated with difficulties to form or safely move the food from the mouth to the stomach. Dysphagia is particularly predominant among patients with neurological diseases, elderly people, and patients with head and/or neck diseases [1, 2]. It is a neglected disorder that has poor prognosis, possibly leading to clinically relevant complications such as aspiration pneumonia, malnutrition and/or dehydration, with negative consequences for the individual's functioning and quality of life [3-5]. When a decrease in swallowing safety occurs, choking and tracheobronchial aspiration result in pneumonia in 50% of the cases, with an accompanying mortality rate up to 50% [1]. The three main risk factors for dysphagia are reduced swallowing safety causing the aspiration of pathogens into the patient's airways, decreased nutritional status leading to malnutrition, to compromised immunity and to frailty, and poor oral health and hygiene associated with the colonization of the mouth by respiratory pathogens [1]. Even though dysphagia is maintained in many cases, [6] in some patients who are in the post-acute phase of the pathology it can actually improve due to functional recovery [7].

As a way of avoiding or reducing some of the complications associated with dysphagia, foods are altered through modification of their texture, or fed through alternative routes that do not include oral intake [6, 8]. These procedures are carried out by trained health professionals in hospital settings, but sometimes are out of the focus of attention of the patients' family members or other caregivers [8, 9, 10]. For patients' caregivers, these dietary changes are sometimes perceived to be abrupt, and the desired food transitions are not successful, namely due to a faulty understanding of the reasons for the changes [8, 9, 10].

Caregivers play a fundamental role in maintaining the patient's safety and health in particular through the implementation of compensatory strategies during swallowing, in compliance with the prescribed diet. It is therefore essential that they are constantly involved in this process, as well as in the process of decision making [2, 6, 11]. However,

research suggests that, in interventions in dysphagia, great communication failures exist between health professionals and the patients and their relatives on the necessity of these changes [7-9]. Studies report that professionals' communication about the risks of dysphagia tends to be based on a punitive and/or technical language, which emphasizes the limitations of the patient, reduces the motivation to eat and makes it difficult for the person to understand the whole process of diet change [6, 7, 12].

Both patients with dysphagia and their family members report the need for more personalized and practical information regarding dysphagia management. Accordingly, some authors state that dysphagia should be approached in a holistic way. Ideally, a specialized professional would explain the risks and consequences involved in dysphagia to caregivers, encourage their involvement in the intervention process, and use appropriate visual references to raise awareness and to help the understanding of some important aspects, such as the texture of the foods to be adapted [2, 7, 8, 13]. Some claim that education about dysphagia should be standardized and made widely available [2, 5, 7, 8, 14]. When oral communication is insufficient or difficult to understand, visual references can contribute to fill in the gaps or even be used in place of oral information [7, 13, 15].

We have not found any studies related with the use of visual elements in communication in dysphagia. However, in other health areas, visual signals have proven effective, and warning symbols combined with education have been widely used in health care to promote safety-appropriate behaviour [15]. For example, in a study conducted in a nursing home, caution symbols combined with education reduced erroneous smashing of medication, which is a well-known and common problem in this context [15]. Standardized color-coded isolation signs were used in another study aimed at increasing knowledge about infection prevention and compliance with isolation precautions among staff members in a hospital [13]. The signs increased team and patient safety, as well as knowledge about, and comfort with infection-control practices and guidelines. The standardized color-coded isolation signs were visible and saved time by providing immediate information to professionals, who did not need to constantly refer to the actual infection of each patient [13].

Visual posters communicating information through signs can be particularly effective if they abide by the principles of design. These include the use of simple elements that contain little detail and that are often familiar, also maintaining semantic relations among them [16, 17]. The combination of colors, words and symbols allows

variations in the levels of danger reported (e.g., red, orange and yellow generally indicate decreasing levels of danger). A triangle containing an exclamation point can further reinforce the level of risk conveyed, indicating risk of personal injury [16].

It is possible that, like in other health care areas, the use of visual signs communicating food procedures to caregivers of patients with dysphagia produce positive effects. Studying augmentative ways of conveying this information is necessary as a way to complement or support speech [18], especially in view of the failures in patient-professional communication about dysphagia, the difficulties of caregivers in adhering to the changes and in understanding their reasons, and caregivers' need for more knowledge on this swallowing disorder reported in research. If visual signs are effective, they can make an important contribution to improving the health and safety of the patient.

The aim of this study is to evaluate the use of a visual poster containing signs about food procedures for caregivers of patients with dysphagia. The goal is twofold: (a) to assess the usefulness of the poster from the point of view of the caregivers, and (b) to assess the impact of the poster on patients' health. If the poster is effective, caregivers will understand it and possibly will change their attitudes accordingly, thus an improvement in patients' health is expected. If such a positive effect is observed, the poster can work as an augmentative means of communication, complementing the information that health professionals deliver.

Methods

This study was conducted in five different inpatient units in Porto, Portugal. Participants were invited for the study, receiving verbal and written information about its goals. Participation was voluntary, and a code was assigned to each case to ensure anonymity. Those who agreed to participate signed an informed consent. The study received ethical approval by the National Commission for Data Protection and by the Ethics Committee of the Northern Health Regional Administration area (ARSN), which is the government organism that oversees all care units in the North of the country.

Sample

The sample includes 42 patients who were eligible to participate at the time of the study. Patients were eligible if they had post-acute dysphagia (i.e., their lesion had occurred at least six weeks prior, approximately), remained in inpatient care for at least one month after the first moment of data collection, were older than 18 years of age or

older, and received regular visits from their family members or caregivers. Patients' caregivers were also interviewed for the study. The characteristics of the sample are presented in Table I.

Patients' ages ranged between 39 and 97 years old (*median* = 80.50), most were women (61.9%), and the most frequent diagnosis was stroke (59.5%), including ischemic (*n* = 14), hemorrhagic (*n* = 5) and multiple (*n* = 2) stroke, as well as cerebrovascular disease (*n* = 4). Other diagnoses included traumatic brain injury (*n* = 3), femoral neck fracture (*n* = 2), heteroaggression (*n* = 1), thalamic hemorrhage (*n* = 1), meningoencephalitis (*n* = 1), Parkinson's disease (*n* = 1), Alzheimer's disease (*n* = 1), dementia (*n* = 1), multiple sclerosis (*n* = 1), Whipple's disease (*n* = 1), peripheral vascular disease (*n* = 1), disuse myopathy (*n* = 1), aspiration pneumonia (*n* = 1), and type-2 diabetes (*n* = 1). Patients' time in inpatient care ranged from 0.17 to 4.21 years (*median* = 0.96). All caregivers were patients' family members and were primarily patients' descendants (85.7%), especially their children (71.4%). Caregivers' level of education varied from illiteracy to college degrees. A little more than half visited the patient on a weekly basis (54.8%).

Instruments

A questionnaire was applied to the patients' caregivers to assess their views about the poster containing the communicative signs on dysphagia-specific food procedures that had been posted as a way to inform them. The questionnaire asked whether the caregiver: (1) noticed any poster in the patient's room; (2) "read" it; (3) found it useful and comprehensively, with the following response options: "I didn't understand it", "I understood it", and "It was very important to me"; (4) considered that it added any knowledge that had not been communicated to them previously, followed by (4.1) which knowledge. Data on caregivers' relationship with the patient, education level and visit frequency were also obtained. Information on patients' age, gender, diagnosis and time since admittance to inpatient care was additionally obtained from patients' clinical files. To assess patients' health status as an outcome of the effect of the poster, four measures of dysphagia-related problems were used: the Gugging Swallowing Screen (GUSS), the Functional Oral Intake Scale (FOIS), the Oral Health Assessment Tool (OHAT), and the Mini Nutritional Assessment (MNA).

GUSS

The GUSS measures the risk of aspiration in dysphagia, and was considered to be the most appropriate scale for assessing patients admitted to inpatient care [19, 20]. It is divided into two parts: an indirect swallowing test (part 1) and a direct swallowing test (part 2). Part 1 evaluates the patient's state of vigilance, cough and/or throat clearing, and saliva swallowing (divided into successful swallowing, drooling, and voice change). Each item receives a "Yes" or "No" score. Part 2 evaluates deglutition (divided into "not possible" corresponding to 0, "delayed" corresponding to 1, and "successful" corresponding to 2), cough, drooling and voice change. The latter three aspects receive a "Yes" or "No" score. The total is the sum of the points obtained in Part 1 with the points obtained in Part 2. The maximum score is 20 points and denotes normal swallowing capacity without risk of aspiration. The minimum score is 0 points and indicates severe dysphagia with a high risk of aspiration [19]. The authors reported a scale's sensitivity of 100%, a specificity of 50 to 69%, with positive predictive values of 81 and 74% and negative predictive values of 100% [19].

FOIS

The FOIS is one of the most effective instruments for assessing the degree of severity of dysphagia because it was designed to identify oral intake capacity, changes in patient daily diet and evolution over time in inpatient care. The FOIS is an ordinal scale that reflects the functional oral intake of patients with dysphagia. Dysphagia is classified in seven possible levels according to its degree [20]. The maximum level is 7, which indicates total oral intake with no restrictions. The minimum level is 1, which means that no oral intake is possible. Interrater reliability was high for this scale, with perfect agreement on 85% of ratings. The Kappa statistics ranged from 0.86 to 0.91. Consensual validity was also high (0.90) [20].

MNA

The MNA is one of the most frequently used and recommended scales for a first level nutritional assessment in all health areas. One of its main advantages is its ability to identify malnutrition risk before the onset of clinical alterations (without the need for laboratory tests). In this study, we use the Mini Nutritional Assessment - Short Form (MNA-SF) that comprises six aspects: body mass index, weight loss, stress or acute disease, mobility, neuropsychological problems, and appetite loss/eating difficulty [21]. Each aspect receives a score that varies (e.g., from 0 to 3 or from 0 to 2). The final score

is the sum of all aspects [21]. The MNA-SF adopted the scores from the original MNA. Its maximum score is 14, corresponding to a normal nutritional state. Its minimum score is 0, corresponding to the presence of malnutrition. The MNA-SF has shown a sensitivity of 75.4% and a predictive value of 79.9% [21].

OHAT

The OHAT is a simple screening tool of eight categories (Lips, Tongue, Gums and Tissues, Saliva, Natural Teeth, Dentures, Oral Cleanliness, Dental Pain) to assess the oral health of institutional residents, including those with dementia. Each aspect is measured on a 0 to 2-point Likert scale. The scores obtained for each of the eight categories are added into a total score. The minimum possible score in this scale is 0, corresponding to a healthy state. The maximum possible score is 16, corresponding to an unhealthy state. The content validity of the OHAT has been established in various studies. For interrater reliability, percentage agreement ranged from 72.6% for oral cleanliness to 92.6 % for dental pain. The Kappa statistics were moderate (ranging from 0.48 to 0.60) for lips, tongue, gums, saliva, and oral cleanliness. For all other categories the Kappa statistics ranged from 0.61 to 0.80 ($p < 0.05$), indicating substantial agreement. Similar results were obtained for intrarrater reliability [22].

Procedures

Patients were randomly assigned to the control and experimental groups (Table 1). Patients' health status was assessed in the beginning of the study (regarding dysphagia severity, oral health, and nutritional status). Then, the poster containing images communicating information on dysphagia-specific food procedures was posted by the bed of patients in the experimental group. After one month, all patients were again assessed for the same health parameters as before. The speech therapist who assessed patients' health was blind as to whether patients participated in the control or experimental group. At the end of the experiment, the family members of the patients in the experimental group answered a questionnaire about the poster.

Created for the purposes of this study, the poster was directed at the patients' caregivers. With a size of 29.7 cm by 21.0 cm, it contained a title ("Guidelines for the family member/caregiver"), a subtitle ("Patient with food difficulties"), a warning sign (a triangle with an exclamation point), and featured twelve images, including human figures, depicting dangers and procedures of feeding the patient with dysphagia. The

images were organized in three rows referring, respectively, to risks (first row identified in red, with four images), adequate food procedures (second row identified in yellow, with five images), and necessary food adaptations (third row identified in green, with one and/or two images). The third row referred to different diets and consistencies for liquids appearing in self-adhesive paper that health professionals posted according to each patient's needs. A brief description of each image also appeared below the respective image. Created by an arts designer under the supervision of speech therapists, the poster was validated prior to this study by a panel of nine people that included experts in dysphagia (e.g., speech and language therapists) and lay people who were ignorant of dysphagia. Their comments were collected via an online questionnaire containing several closed-ended questions (e.g., "In your opinion, only the images (without the words) in the poster are easy to understand?") and open-ended questions (e.g., "What other changes would you make in the poster in terms of Colors, Size/Font, Organization, Structure?"). All their suggestions were integrated in the final version of the poster.

Table I. Sample characteristics

	Total sample *N* = 42		Control group *n* = 21		Experimental group *n* = 21		Difference[a]	
							Test	*p*
Patients								
Age - *mean* (*SD*)	77.26	(12.94)	77.24	(11.36)	77.29	(14.64)	-0.012	0.991
Gender - *n* (%)							0.000	1.000
Female	26	(61.9)	13	(61.9)	13	(61.9)		
Male	16	(38.1)	8	(38.1)	8	(38.1)		
Diagnosis - *n* (%)							0.099	0.753
Stroke	25	(59.5)	13	(61.9)	12	(57.1)		
Other	17	(40.5)	8	(38.1)	9	(42.9)		
Years in inpatient care - *mean* (*SD*)	1.48	(1.23)	1.57	(1.37)	1.38	(1.09)	0.489	0.628
Caregivers								
Education level - *n* (%)	3.60	(1.50)	3.43	(1.57)	3.76	(1.45)	147,000	0,059
Illiterate	1	2,4	1	4,8	0	0,0		
1st year	3	7,1	2	9,5	1	4,8		
4th year	6	14,3	4	19,0	2	9,5		
6th year	9	21,4	5	23,8	4	19,0		
9th year	9	21,4	4	19,0	5	23,8		
12th year	11	26,2	5	23,8	6	28,6		
College degree	3	7,1	0	0,0	3	14,3		
Visit frequency - *n* (%)							2.403	0.121
Daily	19	(45.2)	7	(33.3)	12	(57.1)		
Weekly	23	(54.8)	14	(66.7)	9	(42.9)		
Relationship with the patient							-	-

Children	21	(50.0)	8	(38.1)	13	(61.9)		
Children & Grandchildren	1	(2.4)	0	(0.0)	1	(4.8)		
Spouses & Children	8	(19.0)	5	(23.8)	3	(14.3)		
Grandchildren	1	(2.4)	1	(4.8)	0	(0.0)		
Nieces/Nephews	5	(11.9)	3	(14.3)	2	(9.5)		
Spouses	2	(4.8)	2	(9.5)	0	(0.0)		
Siblings	2	(4.8)	1	(4.8)	1	(4.8)		
Siblings & Parents	2	(4.8)	1	(4.8)	1	(4.8)		
Institutional regime								
Inpatient care duration - *n* (%)							0.525	0.469
Median term	10	(23.8)	4	(19.0)	6	(28.6)		
Long term	32	(76.2)	17	(81.0)	15	(71.4)		

Note. SD – Standard deviation. [a]Difference between control and experimental groups. Test – *t*-test for continuous variables, χ^2 test for dichotomous variables, and Mann-Whitney *U* test for ordinal variables with more than two categories. Dashes mean that a test was not computed.

Analysis

Descriptive statistics were used to analyze the sample, and *t*-tests, χ^2 tests and Mann-Whitney *U* tests were performed to inspect differences between control and experimental groups regarding socio-demographic characteristics (Table I). The questionnaire used to capture caregivers' views about the poster containing the dysphagia-specific communicative signs was also analyzed with descriptive statistics. A thematic analysis was additionally applied to their open-ended responses. Quantitative data were analyzed in IBM SPSS Statistics 25.

After inspection of normality assumptions, General Linear Model (GLM) Repeated Measures were used to assess the effects of the poster on changes from Time 1 (T1) to Time 2 (T2) in patients' health status (i.e., Time*Group effects) regarding risk of aspiration (assessed through the GUSS), oral health (assessed through the OHAT), and nutritional state (assessed through the MNA). The data regarding oral intake (the FOIS) followed a non-normal distribution. Subsequently, the difference between T2 and T1 was computed for these data, for inspection of the effects of the poster on this difference through Kruskal-Wallis tests (instead of GLM Repeated Measures procedures). Covariates included in the analyses were patients' age, gender, diagnosis (stroke or other), and time since admittance to inpatient care. Caregivers' level of education and visit frequency (daily or weekly) were also included as covariates. Bonferroni post hoc tests were used to correct for multiple comparisons.

Results

Caregivers' views about the poster

All caregivers participating in the experimental group responded to the questionnaire (n = 21). All reported that they (1) noticed the poster in the room and that they (2) "read it". All also reported that they (3) understood it, and three caregivers indicated that they found it very useful. Finally, the vast majority (n = 17) considered that the poster (4) added knowledge that they had not received before. The new information received from the poster (4.1) referred especially to risks (the first row in the poster) and adequate food procedures (the second row in the poster). For the caregivers, this new information included the possibility of death (for 7 out of 17), the patient's position while eating (for 6 out of 17), and the possibility of food going into the patient's lungs (for 6, out of 17). Only two caregivers referred the adaptation of food preparation (the third row in the poster) as new knowledge received from the poster (related specifically with liquids consistency). Several caregivers reported more than one category of new information received from the poster (n = 7), namely "pneumonia and death", "fluid consistency and death", or "position during feeding, 90º bed, and extreme thinness".

Impact of the poster on patients' health outcomes

In both the control and experimental groups, patients' health improved from T1 to T2, even if slightly, in all dysphagia-related measures except nutritional state. For nutritional state, improvement was observed in the experimental group alone. Patients in the control group registered the same mean score at T2 and at T1. Table 2 shows the means, standard deviations and the differences between T2 and T1 for each group and for the total sample.

Table II. Patients' health scores: Means (standard deviations) and differences in means between T2 and T1 in the control group, experimental group and total sample.

	Total sample N = 42		Control Group n = 21		Experimental group n = 21)		T2-T1 difference in means	
	T1	T2	T1	T2	T1	T2	Control Group	Experimental Group
Aspiration-risk free[1]	4.62 (2.90)	4.98 (3.07)	3.19 (1.69)	3.33 (1.77)	6.05 (3.17)	6.62 (3.25)	0.14	0.57

Oral intake capacity[2]	2.60 (1.85)	2.79 (1.91)	1.62 (1.32)	1.76 (1.41)	3.57 (1.80)	3.81 (1.81)	0.14	0.24
Oral health risk[3]	8.43 (2.79)	7.90 (2.64)	9.33 (2.35)	8.76 (2.21)	7.52 (2.96)	7.05 (2.80)	-0.57	-0.48
Nutritional health[4]	7.45 (2.80)	7.69 (2.88)	7.05 (2.89)	7.05 (2.80)	7.86 (2.71)	8.33 (2.89)	0.00	0.48

Note. Dysphagia indicators were assessed with [1]the GUSS (minimum = 0; maximum = 20), [2]the FOIS (minimum = 0; maximum = 7), [3]the OHAT (minimum = 0; maximum = 16), and [4]the MNA (minimum = 0; maximum = 14). Higher scores correspond to improved health except for oral health (assessed with the OHAT).

In general, health improvement was greater, after one month, for patients in the experimental group than in the control group. However, the poster yielded significant effects only when the model was adjusted for caregivers' visit frequency. After this adjustment, the poster had a positive impact on patients' health in terms of aspiration risk, $F(1) = 4.222$; $p = 0.047$, and nutritional health, $F(1) = 3.982$; $p = 0.053$, even though the effects were marginally significant. The estimated marginal means for the adjustment to this covariate are presented in Table 3. The effects of the poster on the remaining health measures (oral intake capacity and oral health) were statistically non-significant, even after adjusting for covariates. Also, no other patient (age, gender, diagnosis, or time since inpatient admittance) or caregiver (education level) covariates had any influence on the effects of the poster on patients' health status.

Bonferroni post hoc tests showed that in the model adjusted for visit frequency, the changes from T1 to T2 were statistically non-significant in the control group for both aspiration risk and nutritional health, but were statistically significant in the experimental group for these two health measures (respectively, $F(39) = 11.566$; $p = 0.002$ and $F(39) = 7.233$; $p = 0.010$). In addition, the difference between control and experimental groups was statistically significant at T2 also for both health measures (respectively, $F(1) = 19.891$; $p = 0.000$, and $F(1) = 4.165$; $p = 0.048$), although a statistically significant difference between the two groups was already observed at T1 for aspiration risk ($F(1) = 14.580$; $p = 0.000$), with the experimental group registering a relatively less severe mean level of aspiration risk than the control group at T1. The two groups registered non-significant differences for nutritional health at T1.

The difference observed between control and experimental groups at T1 for aspiration risk was further examined for inspection of its possible influence on the results. For example, it might be possible that patients already with less severe levels of aspiration risk from the beginning (in the experimental group) had greater health improvement over time than those with more severe dysphagia (in the control group), independently of the poster (although the opposite might also be argued, that is, that greater improvement could be expected among those who were worse than among those who were already in better health). The analysis of these aspects suggests the absence of an effect of the difference observed between control and experimental groups at T1 on the results. Analyses revealed that improvement occurred from initial aspiration risk scores of, respectively, 2, 4 and 5 at T1 in both the experimental group (three patients, respectively) and control group (another three patients, respectively). However, the improvement was greater for the three patients in the experimental group (by 2 points on average) than for the three patients in the control group (1 point in each case). Also, aspiration risk scores improved for an additional three patients in the experimental group (by 2.33 points on average) who had scored, respectively, 6, 6 and 8 at T1. Patients with the highest aspiration risk scores at T1 in both the control and experimental groups did not register any changes in this condition from T1 to T2.

Table III. Patients' health scores: Estimated marginal means (standard errors) and differences in means between T2 and T1 after adjusting for caregivers' visit frequency.

	Control Group *n* = 21		Experimental group *n* = 21		T2-T1 difference in means	
	T1	T2	T1	T2	Control Group	Experimental group
Aspiration-risk free[1]	3.08	3.17	6.16	6.79	0.08	0.63*
	(0.56)	(0.57)	(0.56)	(0.57)		
Oral intake capacity[2]	1.58	1.69	3.61	3.88	0.11	0.27
	(0.35)	(0.36)	(0.35)	(0.36)		
Oral health risk[3]	9.39	8.88	7.47	6.93	-0.50	-0.55
	(0.60)	(0.55)	(0.60)	(0.55)		
Nutritional health[4]	6.85	6.81	8.06	8.57	-0.03	0.51 †
	(0.60)	(0.60)	(0.60)	(0.60)		

Note. *p = 0.048. †p = 0.053. Dysphagia indicators were assessed with [1]the GUSS (minimum = 0; maximum = 20), [2]the FOIS (minimum = 0; maximum = 7), [3]the OHAT (minimum = 0; maximum = 16), and [4]the MNA (minimum = 0; maximum = 14). Higher scores correspond to improved health except for oral health (assessed with the OHAT).

Visit frequency alone (i.e., without consideration of control and experimental groups) did not significantly affect the changes from T1 to T2 in patients' health status, indicating that the observed changes were independent from caregivers visiting daily or weekly. Instead, for the two health measures that were influenced by the poster (aspiration risk and nutritional health), scores increased at T2 when caregivers visited weekly, in both the control and the experimental groups. However, the increase was greater in the experimental group than in the control group. In addition, when caregivers visited on a daily basis, patients' health scores remained the same (for aspiration risk) and even decreased (for nutritional health) in the control group, but consistently increased in the experimental group. These changes are depicted in Figure 1 (patients' aspiration risk) and in Figure 2 (patients' nutritional health).

Figure 1. Means in patients' capacity of swallowing without risk of aspiration (assessed with the GUSS) by caregivers' visit frequency: Changes between T1 and T2 in the control and in the experimental groups.

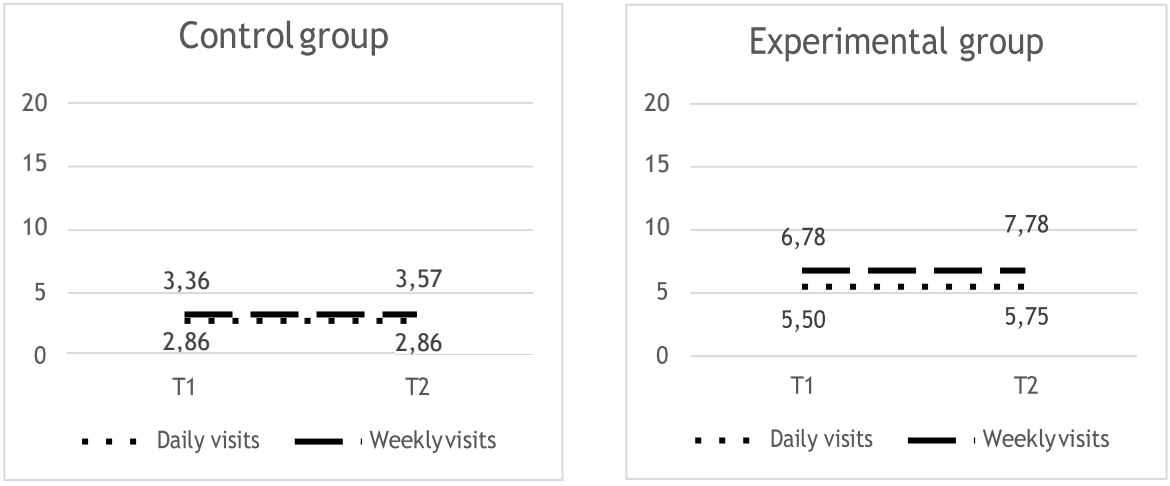
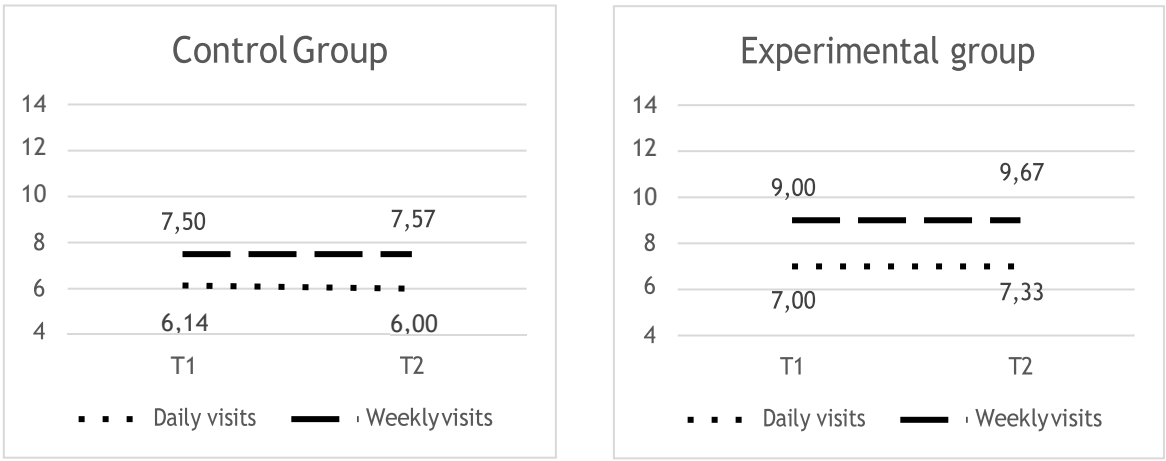


Figure 2. Means in patients' nutritional health (assessed with the MNA) by caregivers' visit frequency: Changes between T1 and T2 in the control and in the experimental groups.



Further inspection with Mann-Whitney and *t*-tests revealed that the two visit regimes (daily and weekly) registered non-significant differences regarding patients' baseline health status (at T1) for all four dysphagia measures. Visit frequency was also unrelated to all other patient and caregiver variables. These results were observed for the total sample, as well as for the control and the experimental groups.

Discussion

Our results indicate the presence of positive effects of the visual poster with communicative signs about dysphagia-specific food procedures as an augmentative means of information provided to the families of patients with dysphagia. This study thus adds dysphagia to previous research also reporting positive effects of visual signs in other health areas [12, 14]. The poster allowed all caregivers to "read" and to understand its materials, regardless of their educational level.This result suggests that following the recommendations for the construction of this type of figurative content was effective [16]. The warning sign at the beginning of the poster might also have helped to draw caregivers' attention because it is a familiar sign of danger [15].

The fact that approximately 81% of the caregivers surveyed reported that the poster added new information to their knowledge reinforces its usefulness. This new

information was mostly related with the risks and the procedures of feeding the patient. The type of diet and food consistency was new only for two respondents, suggesting that previous knowledge obtained on dysphagia focused mainly on these aspects of patient care and neglected risks and adequate feeding procedures. It is however possible that the choice of colors in the poster (risks identified in red, adequate procedures in yellow, and type of diet and food consistency in green) might have drawn caregivers' special attention to the red and yellow, which are associated with (decreasing) levels of danger, and less to the green row. More studies are necessary to explore the extent of caregivers' actual knowledge, as well as its sources.

The efficacy of the poster was also reflected in patients' health, specifically on the risk of aspiration while swallowing, and on nutritional health. The fact that this impact was dependent on caregivers' visit frequency suggests that the information conveyed in the poster was effectively understood and put into practice by the family members. Theoretically, caregivers who visit patients on a daily basis have more opportunities to bring inadequate food and engage in inappropriate procedures when feeding the patients than caregivers who visit on a weekly basis, making it more difficult for the patient's health to improve. Patients whose caregivers visit on a weekly basis, on the other hand, rely on the hospital adequate food and procedures most of the time and can have a greater health improvement as a result. Based on this premise, it could be expected that patients' health would improve less if they received caregivers' daily visits and more if they received weekly visits. This was, in fact, observed in the control group. However, in the experimental group (exposed to the poster), patients' health improved not only when caregivers visited weekly, but also daily.

This possibility needs to be regarded with caution, though. First, the impact of the poster on patients' risk of aspiration and nutritional status was only marginally significant. Second, despite our randomization procedures, baseline aspiration risk was somewhat more severe in the control than in the experimental group, even though mean scores in both groups were within the GUSS criterion for "severe dysphagia with a high risk of aspiration", and well below the cut-off point for the next dysphagia level, "moderate dysphagia with a risk of aspiration" (10, on a 0 to 20 scale) [19]. In fact, our additional analysis showed no evidence that the observed inter-group difference at T1 effected the results, and patients' nutritional state (which also independently improved) registered non-significant differences between control and experimental groups at T1.

Overall, the poster seems promising. It showed positive effects not only from

caregivers' perspectives but also independently on two health indicators, even within a very short period of time (one month).and with a small sample. One month is hardly enough time for any considerable improvement to happen in patients' level of dysphagia, nutrition health, or oral hygiene. The sample size had to do with one inclusion criterion in this study, that patients received regular visits from caregivers. Even with five different inpatient care units involved, this criterion excluded a vast number of patients. One month was used for data collection because a large number of the patients (with caregivers) leave inpatient care after this time. The sample size and time frame in this study might have been the reasons for the nearly marginal effects that were observed. They might also explain the non-significant effects of the poster on two measures of patients' health, namely the change in diet associated with the measure of oral intake, and oral health. Effects of the poster might be more visible in larger samples and more extended time frames, and future studies in other inpatient units can further illuminate these results. Posters communicating though visual signs about dysphagia can also be designed for multidisciplinary teams, potentially including more detailed information than those designed for patients (e.g., maneuvers facilitating deglutition).

In sum, our results suggest that caregivers obtaining information from the poster (namely on risks and adequate procedures of feeding the patient) contributed to an increase in their knowledge, with positive effects on patients' health. Caregivers express the desire for more knowledge about dysphagia procedures, and report that communication of this information is often limited or delivered in technical language [7, 8, 9]. The poster might play an important role in bridging these communication gaps.

Conclusion

A poster communicating information via signs is effective in increasing awareness about dysphagia-specific information among caregivers of patients followed in inpatient care, with benefits for the patients' health. The poster can work as an augmentative means of information for caregivers of patients with dysphagia, thus helping to bridge potential communication gaps between the multidisciplinary team and caregivers about food procedures. It is an economic means of communication with potential benefits for the family well-being and for health-related expenses that could be implemented in hospital settings in the near future.

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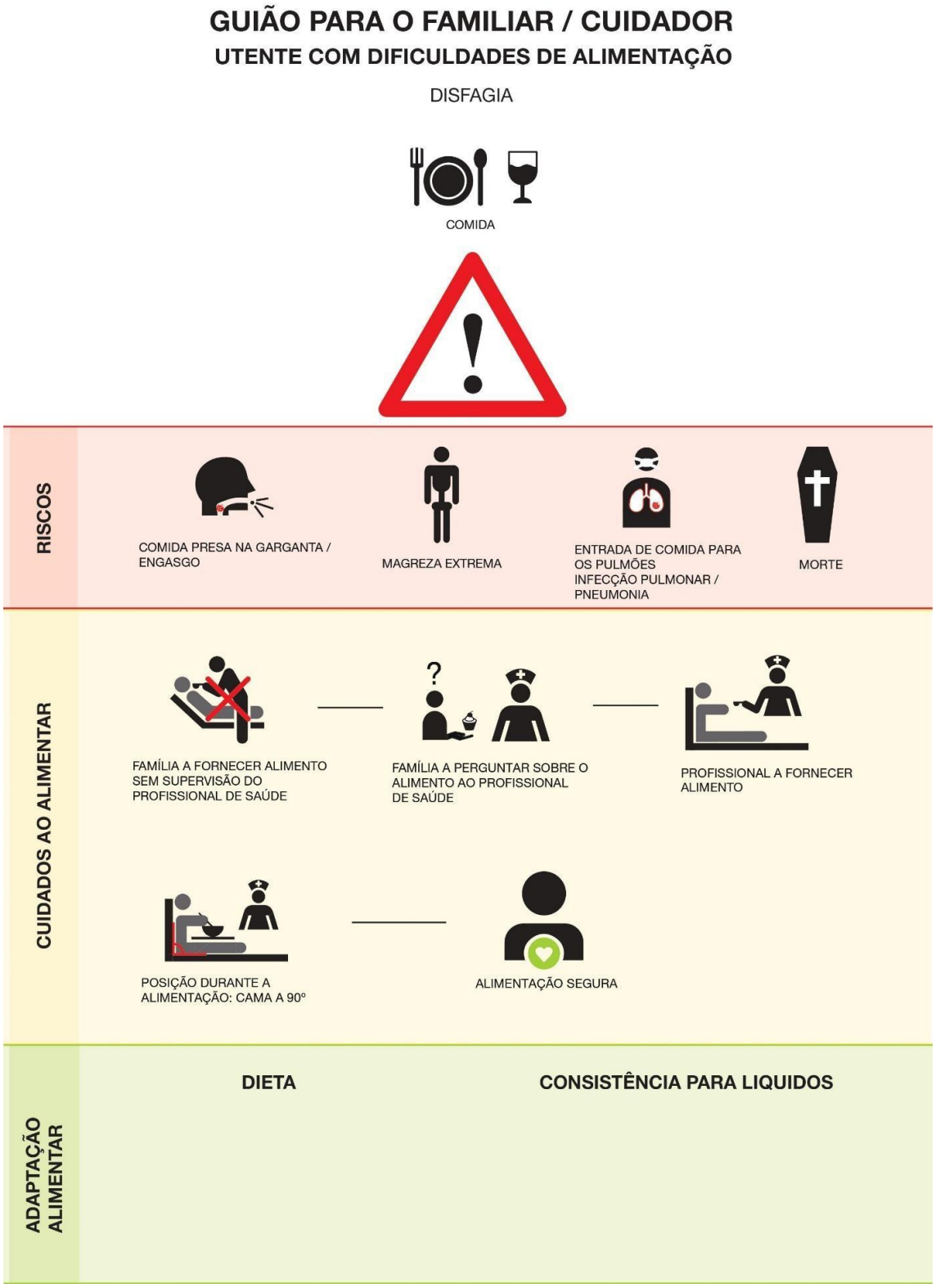
Appendix


GUIÃO PARA O FAMILIAR / CUIDADOR
UTENTE COM DIFICULDADES DE ALIMENTAÇÃO
DISFAGIA
COMIDA
RISCOS
COMIDA PRESA NA GARGANTA / ENGASGO
MAGREZA EXTREMA
ENTRADA DE COMIDA PARA OS PULMÕES
INFECÇÃO PULMONAR / PNEUMONIA
MORTE
CUIDADOS AO ALIMENTAR
FAMÍLIA A FORNECER ALIMENTO SEM SUPERVISÃO DO PROFISSIONAL DE SAÚDE
FAMÍLIA A PERGUNTAR SOBRE O ALIMENTO AO PROFISSIONAL DE SAÚDE
PROFISSIONAL A FORNECER ALIMENTO
POSIÇÃO DURANTE A ALIMENTAÇÃO: CAMA A 90º
ALIMENTAÇÃO SEGURA
ADAPTAÇÃO ALIMENTAR
DIETA
CONSISTÊNCIA PARA LIQUIDOS